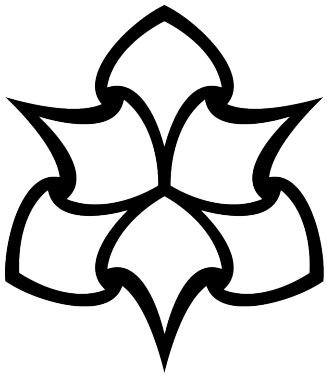

Introduction

This work concerns how psychology as a discipline, as I have experienced it, constructs and measures community care. This is based on my experiences of research, writing and publishing in community based dementia care and care of people with Learning Difficulties (LD). The journey below charts my involvement covering each project and the contributions I have made through my involvement in publishing the evidence/s that lead me to a re-conceptualisation of what care is ontologically, in its very nature, how we see it, or come to see it, its epistemology, and how care is enacted through my observation, in LD and Dementia care research.

The service user participants in my work are situated in comparable care contexts and settings, psychosocial aspects, consequences of care, and lack of a voice. Staff similarity in turnover, poor job-satisfaction, morale and well-being are seen in both LD and particularly Dementia care staff (Jenkins and Allen, 1998, section 1:1, pages, 3-6). Historically care in both LD and Dementia has occurred in large institutional hospital 'back wards'. Such 'total institutions' (Goffman, 1961) enact 'institutional maintenance', through en masse regimes of feeding and daily care; institution's needs superseding individual needs. Both people with LD and people with Dementia lack a voice in terms of personal representation, and communication with staff, and are prone to marginalisation and social exclusion (section 1:1, pages 5-6).

I have a lengthy personal interest in LD, care and quality of life (QOL). This motivation to understand and personal alliance is my guiding position within this thesis, and my published work. This drives my critical stance toward evidence, methods and policy and practices in community care.

Aims and Objectives

My aims and objectives concern: practice and policy, methods used, and my contribution to knowledge in LD and Dementia community care. A lack of practice

implementation of policy concerning a normal community based life is found in private residential care in LD (Paper four, 2008:253, section 3.1, pages 11-15, section 3.3, pages 16-21) and little integrative community contact in day-centres (Paper three 2007:38, sections 3.2, page 15, and 3.4, pages 21-24). Policies regarding tolerance, choice, privacy and recreational activity differ between bio-medical models, and an 'enlightened' social 'model of care in Dementia (Paper one 1996:233, section 3.5, pages 24-28), and gender inequity in care interactions highlights the need for practice and policy intervention (Paper two 1997:344, section 3.6, pages 28-29). My training proposal, (Paper six 2014, section 3.7, pages 29-30) concerns *practice* in increasing the positive interaction by staff. My critical shift (Papers five 2010, seven 2015 and eight 2016) proposes practice applying hermeneutic, discursive and phenomenological principles (section 4, pages 33-45), promoting policies involving the voice of service users, and dialogue between care disciplines.

Briefly here, as methodological critique is ubiquitous throughout this commentary, the method applied yield significant findings, but limitations are noted (section 3:8.2 pages 32-33, section 4, pages 33-45, papers five, 2010, seven 2015, and eight 2016). Measurement of the psychosocial environment, subjective aspects of QOL and care, are better accessed, I argue by phenomenological enquiry.

My contribution to knowledge includes early empirical findings and in papers produced through my critical shift (section 4, pages 33-49, papers five, 2010, seven, 2015 and eight 2016). My early LD private residential care work shows QOL variation between homes, and over time. My Dementia work comparing traditional bio-medical, and an 'enhanced' traditional model and a 'social' model of care, show improvement in resident functioning and more positive interaction within the social model setting.

My observational work contributes to models of care and QOL evaluation, day-centre observation in LD (Paper three, 2007, section 3.4, pages 21-24) and gender disparity in interaction in Dementia (Paper two, 1997, section 3.6, pages 28-29). Observational findings provide material in my training proposal (Paper six, 2014, section 3.7, pages 28-29). My epistemic critical 'shift' (section four, pages 33-45)

aims to reach out in a publication strategy in international inter-disciplinary 'social sciences' and 'caring sciences' journals (Table one, page 10). I deconstruct care, the 'thing in itself', in phenomenological terms, and methods in Papers Five, (2010), Seven (2015) and Eight (2016).

Section 1 Context of the Journey

Firstly, I explain my use of Learning 'Difficulty' and Alzheimer's Disease/Dementia (AD), and main features in the context of community care in the United Kingdom (UK), from the early 1990s to the present day. This is followed by tracing my personal path of research within clinical settings, applying QOL and Social Role Valorisation (SRV) as guiding concepts in care evaluation. I set out key issues with care and its measurement, and its key conceptualisations in SRV and QOL. My criticisms then lead me to a fork in the road this 'critical shift' in thinking, moves away from positivist objectivist approaches toward social constructionism, understood by me as 'being and reality' defined in the myriad interactions with those around us. Gergen (2009:28) maintains "it is from co-action we develop meaningful realities, rationalities and moralities". This section precedes a critical account of my research findings, from my early days through to my critical 'shift' in epistemology and method. I aim to demonstrate the contribution to knowledge I have made in the evaluation of community care, to date, and look toward the future.

1.1 The context of care in Learning Difficulties and Alzheimer's Disease

I use the term Learning 'Difficulties' (LD) reflecting my alignment with a social model of disability (Oliver, 1990a, 2013, Thomas and Milligan 2015) and social constructionist epistemology (Burr, 1995:4, see section four, pp 33-45). Learning 'Difficulties' is preferred by user-led self advocacy groups, such as People First, since the mid 1980s in the United Kingdom (UK, Open University, 2017). This is contrasted with Learning 'Disability' (previously termed Mental Handicap) used by the British Psychological Society (BPS, 2014) and by UK Health and Social Care professions (see NHS England, 2017; Social Care Institute for Excellence, SCIE, 2017).

This commentary is within a ontology of people with LD as social beings first and foremost, subject to social, cultural and professional discourse and practices that potentially perpetuate disability (Goodley, 2001, Oliver, 1990, 1999, 2013). This stands in contrast to models of learning 'disability' underpinned by medicalised pathologising discourse and practices of institutional maintenance (see introduction, page 1). For example, LD as defined by the BPS (2003) includes: significant impairment of intellectual functioning; significant impairment of adaptive/social functioning, and occurring before adulthood. The stark term 'Mental Retardation', still prevails in North America.

I use Learning 'Disabilities' in my publications up to 2015 (paper seven) due to journal editor preference, the use of 'Disabilities' persistence as the disciplinary term in psychology, and academic journals generally.

The 2014 Learning Disability Census shows 46,473 people in contact with LD services across England (Health and Social Care Information Centre, 2015), with a concerning increase in antipsychotic medication, between 2013-2014. This census was prompted by 'Transforming Care: A national response to Winterbourne View Hospital', Department of Health, (DOH, 2012). Winterbourne View was a residential care home for people with learning difficulties near Bristol (UK), uncovered by 'secret' cameras on BBC One's *Panaroma* programme (2012) for a litany of severe physical and psychological abuse by the staff of people with LDs. Hutchinson and Kroes (2015:5) noted Winterbourne's giving serious concern in "appropriateness of existing care provision and practices" with increased risks in specialist residential environments of abuse and neglect. BBC News (31st May 2016) voiced the concerns of families at a 'painfully slow lack of change', and lack of closure of care home institutions such as Winterbourne, wherein "Some 3,500 vulnerable people with learning disabilities are still resident in inpatient units".

The pressing need for humanitarian, compassionate, relational care interventions continues to rise with cases of abuse and neglect such as Winterbourne View, noted above (DOH, 2012).

Learning ‘Disability’ and Alzheimer’s Disease are both contested terms. Alzheimer’s Society UK (A.S. 2017:2) defines Alzheimer's disease as “the most common cause of dementia” as a “set of symptoms that can include memory loss and difficulties with thinking, problem-solving or language”, this is an organic degenerative disease leading to confusion with time and place. Prevention focussed research by Frankish and Horton (2017) suggests social and cultural aspects play a role in social isolation, physical aspects, such as hearing loss, lack of exercise and heart disease as factors embracing a wider bio-social-cultural preventative strategy.

Alzheimer’s Research UK (2017) reports current population estimates of 850,000 people with Alzheimer’s disease (AD) in the UK, rising with increasing longevity to one million by 2025, and to two million by 2050. 38% of the population know a family member, or close friend, living with Dementia and one in three people born this year may live to develop Dementia. Clinically, no new drugs have been approved in ten years, and debatably, little in medical science has changed in clinical intervention. Changing diversity of social care providers is noted, with 57% of people living in residential care, 42% of which are nursing homes and 61% in total, living in the community (Alzheimer’s Research UK, 2017), with long stay institutional Victorian hospital closures since the 1980s. Later (section four, pages 33-49) I frame Dementia within a social constructionist epistemology and the prevailing social and cultural positioning of those with AD as ‘demented’ with age, ‘decrepitude’ and ‘decay’, in a devaluation manifested in care interactions, policy and praxis; ‘praxis’ as practice informed by theory.

One valuable development in Alzheimer’s care is Kitwood’s (1997) social psychological emphasis on ‘personhood’, emphasising biographies, memories and remaining abilities. On a wider level, only a few authors have applied Oliver’s (1983) social model of disability to Dementia (see Beattie et al 2005, Boyle, 2014), Thomas and Milligan (2015:5) attribute this to “the tendency to ignore or sideline older people” and the hegemony of the biomedical model. Attitudinal and institutional ‘social barriers’ highlighted by the social model of disability are examined in their grounding in the realist, materialist position of the social model. This contrasts with the idealist, post-structural deconstruction by Foucault (Tremain

2005) in Thomas and Milligan's review (2015). The social model's realist position is supported by evidence of economic disadvantage and disempowering practices in care systems (Oliver, 2013), contrasting with post-structuralism's concern with the social construction (through knowledge, discourse and culture) of impairment. The social model is criticised for perpetuating the 'conceptual dualism' of 'normal/abnormal', in this post-structural deconstruction by Thomas and Milligan (2015:15). Thomas and Milligan (2015:17) also highlight the 'intersection' of gender, aging and Dementia (see section 3:6, pages 28-29). Thomas and Milligan (2015) highlight the importance of Dementia friendly communities instigated by the Alzheimer's Society and the Joseph Rowntree foundation in 2012. Importance is noted for supportive accepting communities, coupled with technology for safeguarding, through tracking devices, recognising cognitive and short-term memory issues, in Dementia.

The Care Quality Commission's (QQC, 2017:3) 'State of Adult Social Care Services 2014-2017' report states over all inspected adult social care services "too many services are not improving or seem incapable of improving" and "not all services that were originally rated as good maintain quality". This persistence in the fluctuating nature of care is seen in my research (see section three, pages 11-33). The CQC (2017:6) report highlights difficulty in recruiting and keeping staff and lack of staff training; particularly in elderly provision. The CQC reports "Community social care services were rated the "best overall" and "nursing homes remain the biggest concern" (CQC, 2017:8).

1.2 A story of change

What follows from here, in this commentary, is a story of change. Change covering 20 years, beginning in research situated in clinical psychology and psychiatry university departments, practices, and ways of 'knowing', in a world view or ontology, informing the medical model. This helps perpetuate the dominance of the 'clinical gaze' and as Oliver (1990b:2) notes, a view of disability as a 'personal tragedy'.

Reflecting on changes in my thinking over twenty years, there are, inevitably, shifts and contradictions, as there are contradictions between theory and evidence in my early published works. By example (section 3.1, pages 11-12), within my engagement in LD research, Social Role Valorisation (SRV) sits in a social constructionist epistemology, rooted in symbolic interactionist theory; here wider culture is seen as 'the matrix that guides our lives' (Mead, 1934, Crotty, 2003:68). 'Normal' living 'roles' are central in SRV, yet my 'data' is gathered through the empirical means of questionnaires and quasi-behavioural non-participant observation, sorted counted and analysed statistically, according to hypothesised outcomes.

Looking back, I can see considerable tension between a social constructionist epistemology and an objectivist research design, throughout these early days. At the beginning of my research journey, my engagement is in research practices and QOL work influenced by an objectivist lens, using non-participant (rather than participative) observation, following a hypothesis driven 'top down' framework (papers one - four). However, as phenomenology becomes more important to my later thinking, my papers sit in a more sceptical and 'suspicious' take on culture and its influence (Crotty 2003:70). This phenomenological scepticism of the role of wider 'culture' noted by Crotty (2003:71) as "our culture may be enabling but, paradoxically it is also crippling". Merleau-Ponty (1964:181) also mentions the 'taming' influence of culture as 'seeing' by the phenomenological bracketing of our preconceptions invoking "minds renewal, a rediscovery of that brute mind which, untamed by any culture, is asked to create culture anew". Culture is the conveyor of knowledge emanating from professional 'silos', in community care, biomedical knowledge and discourse objectifying the person and exacerbating the dualist normal/abnormal thinking which intersecting with notions of age, and decay. This encapsulates my 'critical shift' within my commentary, moving from an objectivist frame and measures, toward a phenomenological approach in my developing understanding of care practices for people with LD, and Dementia.

QOL is not well understood, nor is its subjective and objective features, in its usefulness for community care research (see section 3:1. page,13). These tensions go beyond quantitative and qualitative measurement but are indicative of

a failure to ascertain the nature of less accessible 'invisible' aspects in care research, such as beliefs and attitudes of staff. The 2014 Care Act (DOH, 2014) puts 'wellbeing' as central, though QOL measures still apply often in national (Cummins, 2013) and individual indices.

'Wellbeing' is useful in this thesis from a care policy level but equally important at the individual level. This more encompassing focus in the UK government 2014 Care Act is examined by the SCIE (2014:1) as including: 'personal dignity and respect, emotional, physical and mental well-being, protection from abuse and neglect, support, participation in work, training, education and recreation, social and economic wellbeing, suitable living accommodation and an individuals contribution to society'. Importantly the SCIE (2014:1) draws attention to individual-personal views, and a 'holistic approach'. Wellbeing is a 'concept' whereas (see section 3:1, pp 13-15) QOL originated in social indicators research, presents many differing measures 'models', concepts and some theory based on national and international research over some 50 years, mostly neither embedded in, nor easily transferable to, community care in LD or dementia. Hopefully, as 'wellbeing' described by the 2014 Care Act, puts the individual and their perceptions at the centre of the process, it may invite a more individualised person centred approach to care research. QOL research rarely achieves this, often concentrating on largescale studies producing population comparisons, intrinsically perpetuating a dualist normal/abnormal framework (Nielsen 2017).

In this section, I have aimed to provide the academic, social backdrop and context of my published work, examined below. My work deals with measures, context and theory, close inspection of life experiences, SRV, QOL and Quality of Interaction (QUIS) observation over time. My QUIS non-participant observation noted what was said and done in hospitals, care homes and day centres, as positive social, positive care, neutral, negative protective or restrictive by type. This in my early years, gives details of original findings in LD and Dementia contexts, and issues leading to my critical shift in thinking about the psychology of care, its ontology, epistemology and practice, leading away from an objectivist account toward a phenomenological perspective.

I now chart research journey with the sequencing of my publications in the following section.

Section 2: Chronology of papers

To avoid confusion, note that I have numbered papers by date of publication. The publication dates do not synchronise with when research was carried out. To address this, table one gives the chronology of research contexts and publication history. My earliest work in the 1990s for example is Paper four, (2008) followed by work on models in Dementia care and the role of quality of interaction, for five years Papers one, (1996), and two, (1997), please consult the table below.

Table one (overleaf) describes 'the journey' with research outputs and contexts.

Table One: Chronology of Research and Publications

The Journey

1990-93, Learning Difficulty private sector residential care research

Paper 4
Skea, D. (2008) Quality of life for adults with learning disabilities in private residential care: monitoring aspects of life experiences over time*. Mental Health and Learning Disabilities Research and Practice.* 5. 2. 252-265

1994-99, Models of care in Dementia and quality of interaction research

Paper 1
Skea D & Lindesay J. (1996). An evaluation of two models of long-term residential care for elderly people with dementia*. International Journal of Geriatric Psychiatry.* 2, 233-241. 50% Contribution *

Paper 2
Lindesay J & Skea D. (1997). Gender and interactions between care staff and elderly nursing home residents with dementia*. International Journal of Geriatric Psychiatry*.12. 344-348. 30% Contribution **

1997-98, Learning Difficulty day-centres quality of interaction research

Paper 3
Skea D. (2007). Quality of staff-service user interaction in two day-centres for adults with learning disabilities. *Mental Health and Learning Disabilities Research and Practice*. 4.1. 37–55.

2000-05 Quality of interaction training proposal

Paper 6
Skea, D. (2014). A Proposed Care Training System: Quality of interaction training with staff and carers*. International Journal of Caring Science*. 7. 3. 750-756

Critical Shift 2006 – to present

Paper 5
Skea, D. (2010) Caring, Quality of Life and Service provision: a perspective*. International Journal of Interdisciplinary Social Sciences.* 5. 7. 195-206

Paper 7
Skea, D. (2015). Deconstructing Caring and Authentic Measurement. *International Journal of Caring Sciences*. 8. 2. 427-434

Paper 8
Skea, D. (2016). Phenomenological Enquiry and Psychological Research in Caring and Quality of Life Contexts: seeing the invisible. *International Journal of Caring Sciences*. 9.2. 1134-1146

See appendix 1 for contribution declarations

Section Three: The Journey

This section concerns the conceptual and theoretical underpinnings of my early work. This covers: introducing the 'life experiences' questionnaire used in Paper four (2008); and the concepts of SRV and QOL as recurring themes in my research journey. Following this section 3.2 covers the development and nature of my extensive observational work in LD and Dementia care contexts.

3:1 Life Experiences, Social Role Valorisation and Quality of Life

My early research (Paper four, 2008) uses the 50 question Life Experiences Checklist (LEC, Ager et al, 1988, 1990, 1998) using concepts relating to SRV (Wolfensberger, 2002) and QOL (outlined below). The LEC was developed in a clinical psychology department, as a measure of QOL in residential care for adults with LD and QOL, in service provision (section 3:3, pages 16-21). The LEC has five sections, ten questions per section pertaining to: home, leisure, relationships, opportunities and freedom. Responses are numerically valued as Yes (1) or No (0) does not apply. Scores are added by subsection and a total QOL score is calculated (Paper four, 2008:258). Example questions include: Home section; 'the décor in my home is of high standard'; Leisure section; 'I go out to café or restaurant at least once a month'; Relationships subscale; 'I have several close friends'; Opportunities section; 'I can make a drink or snack at home when I want to' finally the Freedom scale includes; 'I chose my own clothes'.

Social Role Valorisation

In psychological community care research, the term SRV has replaced Nirje's (1969), term, 'Normalisation' (Banks-Mikkelson, 1969, Wolfensberger, 1972, Wolfensberger, 1983, Wolfensberger 2002, Yates, Dyson and Hiles 2008). The central aim in SRV is providing as 'normal' a life as possible (Wolfensberger, 1972) produced (potentially) by interventions in LD services, this is arguably more action orientated, than the social model maintain Race, Boxall and Carson (2005:8), though both perspectives concern 'promoting support and inclusion in society'. SRV has ideologically influenced policy since the early 1970s, including '*Valuing*

People' (DOH, 2001), though policy and practice links are unclear (Race, Boxall and Carson, 2005). SRV incorporates sociological constructs such as labelling and deviancy, roles and devaluation, particularly 'negative expectancies', and the stigmatisation by the general population of the devalued (Goffman, 1961). This negative concentration upon 'difference' may be questionable (Goodley, 2001, Thompson and Milligan, 2015) in promulgating a conceptual dualism of 'normal/abnormal' creating physical segregation and disabling practices (see introduction pages 5-6). Core themes in SRV include personal social integration and 'valued' community participation through providing normal valued roles counteracting a proposed negative 'social intent' in services, affecting where homes are located for instance, demeaning treatment and institutional regimes.

Wolfensberger and Thomas (1983) proposed services be aware of this 'negative' intents influence on services, in propagating devalued roles, though at an unconscious level, still reducing service users social image and inculcating negative stereotypes in the general population. This negative intent could for example, lead to locating homes and centres near graveyards, in inner city run down areas, placing people in deprived/marginalised areas, giving negative labels to residences and services vehicles, and poor interaction toward service users.

In relation to the SRV yardstick of 'normal' population comparisons and valued 'roles', Goode (1991:3) suggests a 'tyranny of the normal', this together with Hatton's (1998) questioning of who services really serve; people with LD or providers. For example, from a post-structural perspective Jingree's (2015:148) analysis of staff communication of SRV principles and discursive repertoires of 'conventionality' and 'choice' compared with 'normal others', found discourse that restricted choice. This talk was framed within staffs understandings and conceptions of a 'duty of care'. Discourse of 'lacking capacity' was noted to be pervasive in service talk relating to mental capacity and choice for service users.

Expression couched in SRV discourse includes 'devaluation' 'impairment' 'relegation' and 'rejection' 'objectification' and 'non-human' (Race 1999:521). SRV sits within this 'knowledge' system, (creating that which it labels), together with its Symbolic Interactionist epistemology. Here humans are meaning making social

actors, this meaning made through processes of interpretation (Mead, 1934, Blumer 1969, Hewitt, 1984) positioned in a constructionist epistemology. This personal interpretation I argue escapes detection in objectivist 'empirical' questionnaires often seeking prescriptive population 'norms'.

Jones (2013) notes SRV's lack of implementation in both policy and research (DOH, 2001, 2008, Race, Boxall and Carson, 2005). O'Brien (1987, 1992) however, and Tyne & O'Brien (1981) use 'accomplishments' of SRV as service provision indicators, including: Community Presence, Choice, Respect, Relationships, and Competence. Choice, respect and relationships feature heavily in Paper four (2008:259) assessed between homes over time. Wolfensberger and Thomas's (1983) Program Assessment of Service Systems Implementation of Normalisation Goals (PASSING), was used in Flynn et al (1991), assessment of 213 service programs. Community care settings were unsurprisingly better than institutional settings (see Felce, De Kock and Repp, 1986, DOH 2001). This is found in my early papers in both LD and dementia contexts (paper's four, 2008, one, 1996 and two, 1997).

Quality of Life

SRV and overlapping QOL assessment relate to the LEC questionnaire in two ways, firstly private residential care QOL findings in paper four (2008:261) were critically contrasted with that of a general population of 410 adults, a common strategy in both QOL and SRV research. Secondly, LEC questions concerning Home, Leisure, Relationships, Opportunities, and Freedom concern service provision and resident choice, features shared by both SRV and QOL. The policy drivers here are towards a community context of 'integration', and 'normal life' (DSS, 1971, DOH, 1989, DOH, 2001, DOH, 2008, papers four, 2008 and three 2007). I now review what I understand as quality of life.

QOL has been diversely modelled but with little resulting agreement on its nature or constituents (Hincks, in Michalos, 2014, paper four, 2008). QOL measurement and monitoring over time, is focal in my early research in Paper four (2008:253). Early 1950s-1960s research in USA and the UK used 'social indicator' metrics of

income and occupation as objective indicators of QOL (Bunges 1975). Objective indicators include macro level, ‘economic, socio-political, environmental and cultural’ aspects of QOL, note Somarriba and Pena, (2009:120). Felce and Perry (1995:51) propose objective ‘physical wellbeing, material well-being and development and activity’ and subjective “social and emotional well-being” in QOL. Paper four (2008:254) examines subjective and objective features as important ‘conceptual issues in quality monitoring’, though increasingly QOL is seen as a ‘social construct’ (Brown, Hatton and Emerson, 2013:316). Pertinent conceptual and methodological issues in QOL monitoring are examined in Paper four (2008:254, section 3:3, pages16-21) and reviewed below.

Importantly, subjective elements of QOL such as personal satisfaction and well-being (Ager and Hatton, 1999), are viewed as resistant or ‘impervious’ to changes in service provision. I do argue in Paper four (2008:262) that without intervention, only ‘short lived and transitory’ QOL changes are found in my residential LD participants, subjective features remaining largely unchanged over time (Paper four 2008:254), this it is thought (Hatton and Ager, 2002) due to the highly personal nature of satisfaction and well-being and its immunity to changes in service features.

In one way this defends the use of the LEC, as I point out in Paper four (2008) its one sidedness toward the objective, as Cummins (2002) remarks the LEC to be an incomplete measure due to its ignoring subjective features of QOL, but since only objective features are proposed detectable and sensitive to service measurement this gives some legitimacy to its use. I do argue in Paper four (2008), questions do tap into relationships, freedom and opportunities having emotional, subjective implications for well-being, since weekly meetings with friends and relatives, having several close friends and getting on well with ones family were directly asked about of residents with LD on the LEC (Paper four, 2008:259).

QOL is now widely acknowledged as both objective and subjective, shown in the UK 2014 Care Act (DOH 2014) where ‘well-being’ takes precedence (see introduction, page 6). Subjective well-being notes Nielsen (2017:237), in health related QOL “….extends the concept of health beyond the mere presence or

absence of illness or disability". A 'common approach' has evolved with QOL measures equally applicable to a variety of populations (Felce and Perry 1995, Cummins 2013), this can be prescriptive in outcome, and not applicable to the lived experiences of people with LD or Dementia.

I have tried above to highlight key concepts and debates within SRV and QOL from my early research settings of monitoring QOL in private residential LD care (paper four, 2008), and in day centres (paper three, 2007). These differing conceptions have a bearing on what is found (see section 3:3, pages 16-21) in the complex under-studied community context of LD residential care and daycentres.

A further early career feature is my involvement and findings in observation of quality of interaction between staff and people with LD in daycentres and my work in Dementia community based care settings. I now describe this major research feature.

3.2 Quality of interaction observation

The Quality of Interaction Schedule (QUIS) was developed within a 'social model' of care for people with AD, in Lewisham, London UK (Dean, Proudfoot and Lindesay, 1993). In its early form (Clark & Bowling 1989) observed staff interactions in care settings were recorded as 'positive', 'negative' or 'neutral', representing categorisation by main features in interaction, offering comparison between settings. Recently McLean, Griffiths, Eguiagaray, Pickering and Bridges (2017) found QUIS, to be 'reliable feasible and valid' within a hospital study. I was trained in the use of QUIS within Dementia care settings.

QUIS is a non-participant, time sampling observation method, using hand written transcripts noting; Time, Context, Verbal and Non-Verbal interaction, and Interaction types. Interaction types are now coded and scored as Positive Social (PS, scores 5), Positive Care (PS, 4), Neutral (Ne, 3), Negative Protective (NP, 2) and Negative Restrictive (NR, 1). An implied qualitative continuum applies from PS to NR (Dean, Proudfoot and Lindesay, 1993, Bartlett et al 2016, McClean et al, 2017). A 'typical' day is constructed from 20-30 minute observation slots. In PS,

positive social interaction is the main feature, in PC any care orientated interaction, Ne, usually short, cursory interactions that are ‘uninvolved’. NP basically restricts without explanation for reasons of safety and protection, NR restricts without any explanation. My experience of QUIS (detailed in papers one, 1996, two, 1997, paper three, 2007 and six 2014), found NP and NR are rarely observed outside of institutional provision. Interactions are counted and classed by type, ratios calculated by number of interactions and number of residents present, and statistical differences between locations calculated.

The QUIS has been a significant driver for my original findings and contributions to research in quality and nature of interactions in Day Centres (paper three, 2007, see section 3:4, pages 21-224). QUIS was used looking at models of care in Dementia finding significant differences in quality of interaction (paper one, 1996, section 3.5, pages 24-28). Observation findings also include gender differences favouring males in quality of interaction in Dementia care (paper two, 1997, section 3:6, pages, 28-29). I have proposed a training program based on the QUIS findings (paper six, 2014, section 3:7, pages 29-30). Reflections upon this method have also been an important experiential source of questioning in my re-conceptualisation or critical shift (papers five, 2010, seven, 2015 and paper eight, 2016).

I now give an account of my research findings, over time.

3:3 *Quality of Life in private residential care homes for people with learning difficulties*

My journey starts in LD research monitoring the life experiences of 56 adults (aged 18 – 75 years), within six (Social Services registered), private for-profit, residential community care homes (Paper four, 2008). Policy contexts included ‘Better Services for the Mentally Handicapped’ (DHSS, 1971) proposed expansion of community provision, invoking SRV principles, and the 1989 ‘*Caring for People’* White Paper (DOH, 1989) emphasising community care and a ‘normal life’.

Paper four (2008) focuses on the Life Experiences Checklist, though this monitoring project included measures not reported in paper four (2008), including the Normalization Environmental Measure (Beswick, 1989), the Activities of Daily Living Checklist (Davies, 1987) and basic observation of activities (Repp, Felce and Karsh, 1991).

Significantly, Paper four (2008:261) concerns the under-studied private residential care sector and when compared with the general population finds life experiences differ in terms of, “relatively few domestic responsibilities and weaker social networks, but engagement in relatively strenuous programmes of recreation and self improvement”. I also state that a “debateable comparative increase in leisure and self improvement is offset by poorer results concerning relationships and opportunities”. Paper four (2008:261), is explained below.

The LEC, information was gathered over 18 months in face to face interviews with participants, at approximating six monthly intervals, giving three sets of findings, as opposed to a ‘snap shot’. The same people were interviewed in each six monthly phase. Homes include two large urban, two smaller suburban and two small rural homes, sizes ranging between 24 to five beds. Simple feedback reports were given following the three phases (Paper four, 2008:253), summarising life experiences results and the measures mentioned above. 25% of the sample had staff present, acting as advocates due to resident communication problems, this may have distorted findings (Paper four, 2008:255).

The LEC highlighted QOL differences between the ‘normative’ general population (GP), and participants with LD. Poorer QOL was found in Relationships, Opportunities and Freedom of choice LEC domains in the sample; parity on the LEC Home section was seen, and higher scores on the Leisure domain in the sample participants. Specific differences in QOL and service provision included the Home section: 96% of the sample said their homes ‘décor was of high standard’, more than the GP 73%, though weekly use of the telephone was less at 45% compared to 79% in the GP.

The higher scoring Leisure domain included: 80% of the sample going to a ‘café or restaurant at least monthly’, the GP much less at 34%; a similar difference was seen in ‘at least monthly attendance at a club class or meeting’, 84% in the sample compared with 35%. However, 57% of the sample participants had ‘weekly or more, social meetings with friends or relatives’ in the GP this was 70%.

The Relationships domain included just over half the sample (55%) reported having ‘several close friends’ this was higher in the GP (78%). None of the sample reported being ‘sometimes addressed formally’, half the GP sample reported this to be the case. Only 7% of the LD care sample had ‘friends to stay’, in the general population this was 47%.

Freedom and Opportunities domains can map onto SRV choices and rights, and features of QOL. Findings in these domains included: only 13% of the sample chose the home décor compared with 84% in the GP. In terms of rights and normal roles, 52% chose their place of residence, 76% did in the GP. 34% of the sample had a vote, 92% in the GP. 88% however said meals were flexible with their ‘plans’ as opposed to 66% of the GP.

In the Opportunities domain less than half (43%) participated in cooking whereas 78% did in the GP. 55% of participants could make snacks or meals compared with nearly all (94%) in the GP. 45% interviewed as opposed to 23% of the GP were ‘being taught some new skill’. Well-being and SRV features are evident when only 21% of the sample considered their daily occupation of ‘help or value to others’, ‘valued roles’ as central to SRV. Paper four (2008:262), closes with the statement:

> “Results suggest that monitoring and feedback in isolation may not have a lasting effect and that more objective aspects of services may be relatively resistant to enduring change once established”

When life experiences findings by home by each of the three phases of study are compared a statistically significant interaction was seen between home results (as a group) and phase of study. In three of the of six homes, a 12 month significant

rise in QOL, declined at 18 months, to near baseline levels (Paper four, 2008:260). The three (significant) homes included a large 24 place urban home, with 12 resident self advocates (12:17 participants), a suburban 9 bed home, with five self advocates (5:7 resident participants), and a five-bed rural home all self advocating residents. One 15 place urban home showed no improvement over the study (8:13 self advocates). One five place rural home had sustained improvement (all self advocates). Finally, one suburban five place home showed no change from 6 to 12 months, but increased QOL results at the studies completion.

Comparability exists with Ager et al (1988) community hostels LD study and Ager et al (2001) re-settlement from institutions to community residences, both using the LEC. Important to subjective QOL and SRV service provision and planning in Paper four (2008:261) was my noting “fewer social meetings with friends and family” as well as fewer close friends; little perception of value in daily occupation, never being addressed formally, fewer study participants having friends stay overnight, and only half the sample, choosing their residence.

Important findings included lack of training and few qualifications in staff, with no explicit (witnessed) knowledge of SRV concepts, nor notions of QOL, moreover no evidence of such in homes operational policies. Low pay, high staff turnover and insecure employment persists in this sector, Cambridge and Brown (1997, cited in Hanley, David Marsland, 2014:107) note “it is self-evident that poorly treated staff in these insecure and badly paid positions are not the best advocates for other relatively powerless people”. Staff characteristics included seven direct care staff in the largest 24 bed home, three had qualifications one in a direct care role, the 15 bed urban home; with five direct care staff, three with qualifications, the nine bed suburban home’s four direct care staff, one had qualifications, an eight bed rural home with four direct care staff, one with qualifications, both small rural five bed homes had three direct care staff one home had two qualified (ex social services) managers the other, one qualified manager.

My findings above are also reflected in contemporary policy documents focused on the lives of people with LD. For example, ‘A life like any other? Human rights for adults with learning disabilities’ (DOH, 2008) noting gaps “between policy

implementation and actual experiences" this is reiterated by LEC findings, varying by home, between residents and over time (Paper four, 2008:253). Day centre attendance and activities played a large role in this sample, the Leisure and Home LEC sub-sections detected this input with life experience variation over time, and between homes. Further this reflects recent contemporary variations, highlighted in the 2017 CQC report.

Possible distortion of findings could include staff and management presenting their home, practices and procedures, in the 'best light' (Felce and Perry, 1995), in this politically sensitive sector poor results on the LEC reflecting badly on the home and management. This distortion possibly amplified by use of staff proxies in 25% of cases with staff speaking on behalf of residents fearful for their notoriously underpaid and insecure caring roles. Further debate involves acquiescence, the tendency for people with LD to agree 'yes', when the LEC depends upon binary 'yes-no' responding (Rapley and Antaki, 1996). The dynamics of interviewing may include a process of 'shepherding' or coaxing, through interviewers repeating/reformulating questions and influencing responses (Rapley and Ridgeway, 1998) in LD contexts, I cannot rule this out.

Conceptually, SRV ideology emphasising roles and 'Norms' and the positioning of people with LD dualistically in 'normal-abnormal' 'us and them' portrayals, may occlude individual subjectivities, personal differences and lived experiences. Monitoring processes and repeating the interview possibly raised awareness of aspects of QOL, SRV and practices, in four of the six homes. The simple feedback reports given to each home and summarising all findings at the end of each phase may have stimulated awareness. I note in Paper four (2008:262):

> "whatever the causes of the initial increases in scores, the effects were transitory and short lived in all but one home this home participated in a one day quality workshop on 'aims' of the service, quality objectives, action planning and monitoring progress".

The contributions to knowledge in this work importantly includes its focus on the under-studied private residential LD care sector, together with its findings of

fluctuating QOL over time and differences noted between the participants and surrounding populations QOL. Further to this, the hoped enabling stated in Paper four (2008:261) of “the homes concerned to make use of the information gained through feedback” in reports providing “suggestions for improvement at the end of each six monthly” stage, Paper four (2008: 255).

Following training on the QUIS method in AD settings I instigated a further study of quality of Interaction observation in day-centres for adults with LD (paper three, 2007), detailed below, my thinking here was to gain a fuller account of the daily lived experiences of people with LD.

3:4 Observing Quality of Interaction in Day-Centres for People with Learning Difficulties

The 2001 White Paper, *Valuing People*, noted day-centres under performing in ‘promoting social inclusion or independence’ I note this as a motivation for my research in paper three, (2007:38).

Using QUIS observation in LD contexts had not been done before this study, as behavioural and ‘task engagement’ observation dominated LD institutional and residential care (Prior, 1979, Felce, DeKock and Repp, 1986, Markova et al, 1992, Simpson, 1998) contexts. Little observation had been done in day-centres (Seed 1988, Collins and Toft 1999). Bringing quality of interaction to this under-researched area, I saw as a clear contribution to research and knowledge.

The Symbolic Interactionist perspective (Mead, 1934, Stryker 1980) whereby Hewitt, (1984:9) describes experience as “actively created as we act in and toward the world”, guides my thinking in Paper three (2007:39) connecting social interaction to QOL, Mental Health, and SRV. I note here; ‘poor quality of interaction can decrease self-perceived status and have detrimental effects on self esteem’. I propose that quality of social interaction is as important as the physical aspects of care and activity/engagement.

Early work by Prior (1979) highlighted controlling and directive speech by staff in institutional settings. In LD, 'traditional institution' research consistently observes negative and neutral interaction types. Given this I was motivated to observe quality of interaction in day-centres in this context of SRV implementation, in a sector with sparse observational evidence.

Two day-centres were recruited, a suburban, converted, originally a private residence DC1 with between 46 and 50 service users, and a city centre, purpose built open plan DC2, with 247 service users. Centres were run by the same Social Services management team. Time table inspections and brief interviews with managers in centres showed activities with 20% of time in Leisure for both centres, Work 23% in DC1, 28% in DC2, Education accounted for 1% in each centre and community orientated activities such as shopping, outdoor pursuits, environmental projects and community visits at 3% in DC1, 6% in DC2. Published quality frameworks for both centres (unlike the operational policy statements in my above residential study) showed awareness of SRV and QOL features such as 'encouraging independent action' and 'positive public perception', and use of a 'presence in the surrounding community' (Paper three, 2007:48).

Previous research by Seed (1988) and Pettipher and Mansell (1993) implied that a higher rate of interaction would be found in the smaller day-centre, DC1, of a positive nature, in DC1. Higher rates of interaction would be found when staff work singly with groups of clients, than groups of staff with groups of service users (Felce and Perry, 1995).

A significantly higher rate of interaction was indeed seen in DC1, consisting of more PC than PS interaction types, the opposite seen in the large DC2, more PS less PC. In DC1 more non verbal and verbal interaction was seen, and in DC2 more purely verbal interactions, more staff initiated interactions in DC1, whereas more client initiated interactions were noted in DC2. Seed (1988) and Collins and Toft (1999) noted more interaction if it involves structured activities, this was found, with longest interactions occurring between 11.30-3.00pm in each centre. In Paper three (2007:47) I note interactions 'relatively complex, often explanatory or

instructional in nature; embedded within activity sessions, structured activities and the lunch period'.

Results indicated 'Richer' more positively engaged interaction in DC-1 where staff observed working alone increased staff interaction with service users (Felce et al 2000). Service users in DC-2 appeared to compete for staff attention in their large often noisy, open plan environment; making observation difficult. NE, NP and NR were very rarely seen in either centre. I describe the considerably larger DC-2 setting interactions as more likely to be "purely social in nature, purely verbal, very brief and often initiated by the service user" (Paper three, 2007:49). Findings are comparable to Pettipher and Mansell's (1993) study in terms of percentage of time in interaction indicating limited depth/interactional involvement and quality of interaction. I note in Paper three, (2007:50) that the smaller centres higher rate of interaction may be due to the 'physical layout' of DC1 originally a normal large multi-roomed dwelling house, and 'small groups working with a single staff member' in this setting. In the larger DC-2, pairs of staff often worked with larger groups. Though more PS was seen in DC-2, importantly its nature does not translate to higher quality of care, inter-personal involvement or quality of interaction, a significant finding in itself for interpretation of QUIS findings.

Observation in residential care and day-centres (Felce, DeKock and Repp, 1986, Markova, 1992) is often 'behaviouristic', calculating *quantity* of interaction, activity allocation and 'active support', *quality* of interaction is rarely mentioned. The QUIS, I see as Neo-behavioural in the sense that it goes beyond quantification by implying a qualitative, involved dimension, as opposed to behaviouristic observational research in LD. This bringing in of a qualitative dimension to interaction through the use of QUIS, takes behaviouristic quantification further, and gives contributory understanding of this under researched LD context.

My observational work (Paper three 2007), suggests a lack of policy and SRV features for providing 'normal' roles and community contact through community based interaction. Furthermore, a lack of activities that were social skills based, indicating a lack of preparation and centre input for involvement with the surrounding community. This together with the poorer relationships with family and

friend support networks, freedom in various choices and opportunities in the surrounding community, noted in residential 'life experiences' and the transitory changes in the QOL measured, suggests shortfalls in policy and SRV realisation (DSS, 1971, DOH 2001, DOH, 2008) with an unstable, fragmented service quality, and issues with Human rights and equal treatment to enable an integrated community based life, 'presence' in the community using community based resources and sense of 'value' - noted in my residential care work where very few participants thought they did work they thought to be of 'value' - Paper four, (2008:259).

Before my observational work, I had started work in research in Dementia (see table one, p 8), where my training in the QUIS method occurred. This work is centred on 'models' of care, gender differences, and measures of service provision for people with dementia and their staff. The QUIS method plays a large role in my work below.

I now move onto my research in dementia care.

3.5 Quality in Alzheimer Care Provision: comparing 'Models' of Care

Comparisons with the above LD findings is possible when comparing institutional to community based care, I do not in my sole authored nor co-authored work, define institutional compared to community based care (this is surprisingly common in community care research). By institutional, I mean large congregate hospital complexes and open plan same sex wards, these large Victorian Asylums staffed by uniformed nurses, doctors and allied professionals. Block treatment, that is treatment 'en masse' (Goffman, 1961), occurs to rigid schedules of toileting, feeding, dressing, sleeping and awakening. Both contexts are just as prone to institutional maintenance practices – the service working for the good of the service not the service user - and staff fears of accountability.

In my Dementia work the context is that of QOL and 'models' of care provision. The 'models', I view on a qualitative continuum from traditional institution at the outset/baseline of the study – to new community based NHS hospital – and a

further ‘social model’ partnership facility, between the NHS and a charitable specialist housing organisation (paper one, 1996). The political, policy and social care context is of rundown and closure of traditional NHS long-stay hospital provision leading to community based private sector and partnership (NHS/and other) model ‘solutions’. This increased range of care providers emphasising a community location. Previous comparisons of long stay institutional provision and community based units in Dementia care had shown measurable increases in cognitive functioning, communication and self care in residents. Good well-being and job satisfaction in staff is noted, together with improved Interpersonal interaction involving staff and residents (Clarke and Bowling 1989, Dean, Proudfoot and Lindesay, 1993, Jenkins and Allen, 1998). Policy improvements were noted in resident’s choice, control, and access to social and recreational activities (Lindesay et al, 1991, Dean, Briggs and Lindesay, 1993, Shepherd, Muijen, Dean, and Cooney 1996). This was the research context, the backdrop, to my early work in Dementia (paper one, 1996).

The measures I used to assess QOL and care provision in Dementia involved participants with Dementia and their staff. Firstly, each locations unit policy was measured using the Policy and Program Information (POLIF, Timko and Moos, 1991)) from the Multiphasic Environmental Assessment Procedure (MEAP) concerning ‘behavioural requirements’; ‘balance in institutional order, and individual freedom’; and ‘availability of services’. POLIF profiles in Paper one (1996:233) concern an institution at baseline and Unit one (Un1) a 24 bed, two six bed, two four bed and four single rooms lay-out; new community hospital ward, and Unit two (Un2) a partnership between a mental health service NHS regional trust and a charitable organisation with ‘expertise in special housing needs’ (Paper one, 1996). This facility was ‘free standing’ and ‘purpose built with four separate though linked nine bed ‘house groups’ (Paper one, 1996:234).

The baseline institutional ward policies and programs were compared at one, six and twelve months with that of Un1, caring for 15 female and four males (average age of 78) all primarily diagnosed with severe Dementia, and Un2, with 24 males and seven females (average age of 77) the primary diagnosis again was severe Dementia.

The new community hospital (Un1) policy profile as stated in paper one (1996:233) provided an “enhanced version of traditional hospital care”; shown by significant policy improvement in policy clarity; social/recreational activities, policy choice, privacy, availability of health services, and daily living assistance reflecting increased health and care support for residents. The Un2 policy profile was that of an ‘enhanced social model’ showing important improvements in tolerance of deviance, policy clarity, choice, and privacy with 100% ‘availability of health services’ and daily living assistance. Un2 also significantly improved in social and recreational activities at one month and 6 months, but decreased at 12 months the loss of their social and recreational officer (Paper one, 1996:236). Un2 shows a similar policy and program profile to that of the Domus care system, where social care and tolerant policies are central, (Lindesay, Briggs, Laws Macdonald and Herzberg, 1991 Dean, Briggs and Lindesay, 1993, Dean Proudfoot and Lindesay, 1993:819). Domus care research notes “greater expectations for resident functioning” including attention to psychological and the emotional needs of residents (Lindesay et al, 1991:122).

Relocated residents, all of whom had severe Dementia were less mobile and “more dependent on total nursing care than those remaining in hospital” were assessed (Paper one, 1996:237) for cognitive impairment using the Organic Brain Syndrome (OBS, Gurland et al, 1977) and depression using the Depressive Signs Scale (DSS, Katona and Aldridge, 1985), recorded by staff. Resident Self Care, Mobility, Communication, Orientation, Disturbance and Aggression were measured using the Adaptive Behaviour Rating Scale (ABRS, Woods and Britton, 1985).

Greater depression was recorded in the baseline hospital sample and higher cognitive impairment for those moving to Un1, compared to residents re-located to Un2, depression increased at 12 months on Un1 and significantly decreasing in Un2 residents. No change in cognitive impairment was seen in relocated groups at six or 12 months. The ABRS findings showed increases in mobility, and recognition of visitors as well as substantial and significant improvement in communication. Un2 mortality was 48% and these findings were not due to ‘survivor effects’ where residents were more robust ‘ab initio’, or likely to survive longer. This pattern again

is similar to the earlier mentioned Domus research, where differing 'model' services produce real effects on resident cognitive, behavioural and self care functioning. Importantly differences were noted in staff general psychological well-being and occupational satisfaction, with staff in the new community hospital, relocated like the residents, from the institutional hospital environment.

In Un1 a minimum of two qualified nurses, three nursing assistants and a ward aid attended each shift; giving a 1:4 staff to resident ratio. Un2 were recruiting so no baseline staff measures exist for this unit, later shifts though included between three and four qualified staff and eight residential, unqualified support workers, giving a staff to resident ratio of 1:4.5, similar to Un1. Staff job satisfaction was measured using the Minnesota Satisfaction Questionnaire (MSQ, Weiss et al 1967) and well-being assessed with the General Health Questionnaire (Goldberg and Hillier, 1979). Though Un1 staff satisfaction was the same as their baseline levels at six months, at 12 months it had improved to that of 'medium levels' in nursing staff (Weiss et al 1967). Un2 staff had significantly higher satisfaction than Un1 staff, at 12 months. Staff psychological well-being on Un1 indicated increased well-being at six and 12 months following relocation with a rate of psychiatric 'case-ness' falling from 25% to zero between baseline institution and 12 month Un1 follow-up. Un2 staff showed increased well being between six and 12 months, and 'caseness' of 12% at 12 months. Comparisons again with the Domus units of Dean, Briggs and Lindesay (1993:727) are possible in "no evidence that staff suffered from low job satisfaction or psychological impairment".

QUIS observation in baseline hospital wards was done and findings compared with Un1 at 12 and 24 months and Un2 at six and 12 months (Paper one, 1996:238). The rate of interactions per resident was low at baseline (4.3 per resident) in Un1 and at 12 months this was only slightly improved (4.9 per resident) however feedback encouraging improvement led to a significant improvement at 24 months (7.9 per resident); PC interactions doubled between 12 and 24 months, though PS fell slightly over the same period. In Un2 significantly more PS and PC occurred at six months compared to the institutional baseline findings, this PS and PC increased at 12 months, without feedback. Comparisons at 12 month between both new community units gave more PS and PC and Ne interactions in Un2.

Research contributory findings are comparable to earlier Domus observational findings (Paper one, 1996:239, Dean, Proudfoot and Lindesay, 1993). Here socially 'liberal' environments which are tolerant of 'deviant' behaviours, give residents more control, choice, privacy, recreational activities, daily living assistance, with staff care and social interactions which are largely positive (Paper one, 1996:236). This excels over a community based 'enhanced traditional hospital model' (Un1). This highlights the importance of differing models of care for residents, staff and institutional maintenance processes. Though not verifiable, it does raise the possibility that relocated staff relocated their medical model/beliefs with them, in the enhanced traditional care of Un1, ostensibly a community hospital.

3.6 *Gender differences in quality of interaction*

The recognition of gender and gender inequality in Dementia care has been largely ignored, with important policy implications (Bartlett et al, 2016). This section adds to knowledge on differences in care dependant upon gender, as an overlapping feature of identity (see Thomas and Milligan, 2015, below).

Paper one (1996) suggests a possible reason for differences in Un1 and Un2 could be gender differences between staff and residents in each environment, specifically a higher proportion of male residents in the partnership Un2. QUIS transcripts were modified to note who initiated interactions by gender. Findings include male residents initiated more interactions with staff regardless of staff's gender. Female residents initiated no interactions with male staff and female staff initiated more interactions than male staff. Interestingly, male and female staff initiated more interactions with male residents than female residents. The stereotype of women as the more talkative gender (Tannen, 1993) is unsupported; but complex relationships are suggested (Paper two, 1997) for status, age, race, mental capacity, 'roles', physical mobility and elderly male expectations of care from female staff. Female residents may be at a QOL/social interaction disadvantage in high dependency care environments. This paper is cited in gender and Dementia care policy, and research by Bartlett et al, (2016) and others

(McClean et al, 2017) and represents a unique contribution to Dementia knowledge which still has some contemporary impact.

To conclude, from a theoretical perspective, findings may be evidence of a care outcome involving 'Inter-sectionality', stated by Thomas and Milligan (2015:11) as "overlapping fragments of our identities" in this case the overlap of gender, age and Dementia as impediments to care treatment, an area for further research and intervention.

Key contributions and findings in this section cover the under researched community contexts where my LD research occurred, my private residential QOL monitoring work and findings, and my unique day centre QUIS observation findings. The significance of fluctuating QOL in private residential care settings, poor comparisons on QOL with study participants and the general population and effects of monitoring and feedback per se (section 3:3 pp 14-18). My Dementia work highlights the differences in policy, staff and resident outcomes of differing models and environments of care together with the need to focus on gender in Dementia care.

Following this work, I became a senior lecturer in psychology; this provided a chance for reflection furthered by teaching, seminars and public talks, about my findings. During this pedagogical move (2000-2005, see table one, page 10) I developed a framework Quality of Interaction training program, belatedly published as Paper six (2014), though presented as an idea at a Cambridge University conference, several years earlier.

3.7 Training in Quality of Interaction: possibilities

My thinking here was, the QUIS method is applicable across a number of contexts and training in communication skills and interactive methods in health, (Lane and Rollnick, 2007, Hargie et al, 1997, Ments, 1999) and learning theory (Kolb, 1984), suggesting a potential training intervention. I adopted again a Symbolic Interactionist perspective to caring, invoking 'reflected appraisal' and affective consequences in caring interactions, rather than a 'behaviouristic' perspective.

Staff are usually seen to be “supporting task specific behaviours” in paper six (2014:750), I propose “quality of interaction is seen as important in quality of life, since how we are treated effects how we appraise ourselves”. Quality of interaction is seen as intricately linked with delivering highly compassionate relational care (Dewar, 2013, McLean et al, 2017). Dewar, Adamson, Smith, Surfleet and King (2013:1744) note “the small acts that matter” in other words interactions of staff when caring compassionately in a relational manner. Compassion defined by Chochinov (2007, in Dewar (2013:49) as “a deep awareness of suffering of another coupled with a wish to relieve it”. Dewar (2013:49) importantly notes a role for self awareness of staff and compassion towards the self in maintaining compassionate and relational care toward others.

My proposal adopts Ment’s (1989, 1999) systematic role play (Paper six, 2014:754) involving roles where PS, PC, Ne, NP, and NR interactions are ‘acted out’ as roles in demonstrable vignettes, including a briefing, demonstration and reflection sessions within this program adapted from Ments, (1999). This proposes my idea of a two way role play using a 3rd person rotating observer, where everyone plays the roles of, observer, carer and being cared for. This followed by debriefing, clarification and reflection on the process.

This personally driven creative exploration into training research, learning processes and applying the QUIS is I note “also proposed to be cost effective, measurable and flexible enough to mature with the feedback of those taking part” in paper six (2014:750). This paper is a unique contribution to the field and I believe deserves further research. This paper is referenced in Mclean et al (2017) QUIS validity and reliability study, suggesting some contemporary resonance as an application of the QUIS method, paper two (1997) findings are noted in Bartlett et al (2016) scoping review of gender in Dementia care informing care policy .

Section 3:*8 Key reflections on the early years of my research*

In this section I set out further key personal learning outcomes and expand on my contributions by publishing within LD and dementia care. I review each of these in turn below. Briefly this concerns the physical size of the environment in care

delivery, limitations in questionnaires and assessment methods including the QUIS method.

3.8:1 *Size matters*

In both LD and Dementia contexts, size is a key feature. I find (approximating) 'normal' sized care environments, for this purpose the smaller private residential LD care, 5 – 9 bed homes, exhibited better QOL scores (Paper four, 2008:256). The partnership unit 2 offered smaller inter-connected care spaces (Paper one, 1996:234, and two, 1997:344), and the smaller (originally residential property) day-centre environment (Paper three, 2007:41). The above show a higher rate and greater proportion of both positive care and social interaction; particularly when single staff members work with single groups of people (Felce and Perry, 1995). The baseline large hospital Dementia care wards (paper one, 1996) and large day centre observed in LD (paper three, 2007) show largely the opposite of this.

Reflecting further, this work has complex interacting features such as; gender of resident and staff, staff training, well being and satisfaction, together with more 'enlightened' socially orientated policies and practices 'acted out' in smaller environments, as described particularly in paper one (1996). Size of the care environment – the work space as such - is related to observed positive care and social interactions as I have noted, to the extent that in the larger day-centre of paper three (2007), participants appeared to vie for the attention of staff, affecting the shape of interaction itself, in shorter (cursory) interactions from staff. Such findings lead me to further issues, particularly the limits of measurement, per se.

3:8.2 *The limits of measurement*

To my mind there are some limitations to quantitative measurement in 'real life' care spaces, as I have experienced them.

Criticisms include the LEC lack of comprehensiveness as a complete measure, particularly of the subjective features of well being and satisfaction in QOL, noted particularly by Cummins (2001:3, 2005:700) cited in Paper four (2008:254). In

addition its binary choice ‘yes/no’ response format, when there may be a chance of acquiescence, the tendency to respond ‘yes’ to questions in the belief that this is what the interviewer wants to hear. This has two sides, I cite Rapley and Antaki (1996:376), in that acquiescence in LD is “conceptually cloudy” and “empirically unproven” and that “inconsistency is often confounded with acquiescence” in paper four (2008:255). General issues include the limitations of structured inflexible questionnaires, confining what is found with pre-ordained questions and responses. This method is typical of psychological research where individual variation (and real meaning) is lost in producing averages and population distributions. This nomothetic approach hiding individual personal life experiences, found through one to one semi-structured (flexible) explorative interviews for instance; the ideographic approach.

Several points come to mind in my research findings using QUIS as an observational system. Though not verifiable (as QUIS transcripts no longer exist to check) studies such as Jingree’s, (2015) highlight discursive repertoires of staff in their duties of care that serve to restrict choice. This discourse could have been recorded and coded as positive interaction, when the opposite, in effect is true in its negative restrictive outcome. QUIS cannot note what may be unconscious unintended consequences, though discursive and textual analysis can.

I note in my recent work in paper seven (2015) that discourse analysis may have been possible on QUIS transcripts as I have noted (above) the over use of discourse involving infantalising language, researchers also note over-verbalisation with non-verbal service users and over-questioning (Prior, 1979), all aspects which can induce discomfort in service users, with an equal negation of staffs effectiveness.

McClean et als (2017) study notes a QUIS 75% inter-observer agreement level over multiple studies, this leaves 25%, one in four, differently observed behaviours between observers. This together with a scoring method that gives (non-engaged) Neutral interactions a score of 3 and Positive Care a score of 4 (McClean et al 2017) suggesting poor discrimination between positive and Neutral and importantly, Negative interactions. The presence of the observer has been noted

as having potential inhibitory effects on staff behaviour in McClean et al's (2017) study, though it could cause an opposite Hawthorne effect an 'acting up' of 'socially desirable' demonstrations of care, at least in some observations. My presence as 'the observer', its non-participatory nature, couched in neo-behaviourism and basic positivist underpinnings and practices, suggests findings should be treated with caution.

The above limitations in the measurements I have used, and theoretical and conceptual issues I have drawn attention to in my introduction (pages 4-6) and section 3:1 (pp 11-13) gave rise to a personal repositioning. The remainder of this work depicts my re-orientation and critical shift in my thinking on measuring and viewing community care. This leads me to section four below, exemplifying this 'critical shift' in my thinking.

Section 4: The Critical Shift in thinking

I define 'critical shift' as a process of re-conceptualising the ontological nature and epistemology of community care, that is what 'care' in essence, is, the nature of 'it' in itself (ontology); and how we come to know and understand its very nature and processes (epistemology). This led me from my previous understandings, in my search to understand. How this was done is explained below.

4.1 Discourse and power: deconstructing care

My emerging experience in teaching and supervision in higher education particularly of qualitative methods and service evaluation projects led to me reflecting on my early years experiences of research. Unsatisfactory conclusions include "underlying assumptions" of measurement, "features of epistemology, methodology and methods" and how they are "unchallenged in the rush for objective empirical data" I note in paper five (2010:1) and how this may hold back progress. This led me to look to the roles of discourse and power, differing types of phenomenology and further critical examination of care and QOL, within the changing shape of care and who does the caring in the UK.

Here discourse and power is understood through the French, idealist poststructuralist writings of Foucault (1972, 1976, 2003) and how discourse reflects societal constructions of LD and people with Dementia. This with institutional growth through asylums and prisons (Goffman, 1961) propagated in culture through professional knowledge and practices, giving the enduring hegemony of the biomedical model. This is noted below, from Thomas (2007:81):

> "The cultural, the discursive and the linguistic have assumed pre-eminence in poststructuralist theorisations of disability and impairment" where realist, materialist theory is "dismissed as modernist grand narratives……with conceptual dualism: abnormal/normal, disabled/non-disabled……"

This to me presents a way forward in deconstructing the psychological construction of community care. In a sense rather than saying 'what is the difference/s', what is it about us, our culture, our professions, environments and practices, that reinforces and promulgates differences between us and those with LD or Dementia.

This deconstruction includes post-structuralist methodology including Critical Discourse Analysis in its multidisciplinary interest in as Wodak and Meyer (2009:30) portray "demystifying ideologies and power through the systematic and retroductable investigation of semiotic data, written spoken or visual" (Fairclough, 2009, Parker 1989, 2007). Foucauldian analysis presents a perspective where people are 'subjects', within knowledge systems, power and its techniques (distortions) such as ageist, fatalist, disabling discourse, in social-political systems (health and care services). This relates to QOL and its comparative approaches seen in my early research in LD care and psychological constructions of, the care of, 'impaired' people (Foucault, 1972, 1982, Tremain, 2005, Jansen, 2008, Phelan, 2010, Yates, Dyson and Hiles 2008).

This world view or ontological re-interpretation helped me to deconstruct care, QOL, SRV and measurement embedded in the psychological construction, of community care (papers five, 2010:1, and seven 2015:427). In 'Deconstructing care and authentic measurement' paper seven (2015:429), I propose a 'stripping

back', where "the term authenticity in this work is meant to portray a qualitative version in some sense as that of validity in positivistic empirical research……to seek the goal of a deeper understanding of care" moreover caring "is still rooted in interpretation and cultural historical knowledge structures in all their permutations" noted in paper seven (2015:427).

Further an interest in phenomenology dating back over ten years and lately (Paper eight, 2016) involves looking at phenomenology's often ignored philosophical roots (Giorgi, 2008:1) in Descriptive, Husserlian Phenomenology (1859-1938) and Heideggers' (1926-1962) Interpretative Hermeneutic Phenomenology (Giorgi, 2000:11, 2008:3). The positioning here of the researcher and the 'natural science' method being starkly different to an awareness of co-constructions, in inter-subjective social worlds. Heidegger's (1962) Interpretative Phenomenology informs, Interpretative Phenomenological Analysis (IPA, Smith, Flowers and Larkin, 2009) a method I explore later in this section. It needs noting that my earlier Symbolic Interactionist perspective and Phenomenology take a different perspective on cultural/wider processes (introduction, pages 5-6). Phenomenology is more sceptical of these wider processes, in that the lens for seeing things as they are is misted/contorted by internalising cultural beliefs and values (enculturation) and our lived in culture (see introduction, page 6). This I hope helps explain my critical shift and move to dissatisfaction with SRV and the limitations of my assumptions and that of Symbolic Interactionism.

4.2 *Understanding measurement*

My critical shift in thinking about measurement is exemplified in paper five (2010) and a conference presentation at the university of Cambridge UK. Here I propose that due to policy, political, and practice issues in the field, that the "rush for objective empirical data" paper five (2010:1) has impeded the answering of critical questions concerning QOL in care contexts. A further impediment is the mostly unquestioned assumptions underpinning measurement and whether care is measurable at all.

A constructionist conceptualisation is proposed here to help the impeded "development of theory and practice in the field" I note in Paper five (2010:1). Elements of hermeneutic enquiry and phenomenological psychology are proposed to reveal and 'decipher' what QOL and QOC are, in their traditional 'top-down models' (not theories as the field is largely a-theoretical), and how they could be assessed in very 'complex' caring environments. Assessment at best, by neo-behaviourist observational systems (QUIS), a dearth of model driven questionnaires, rating scales, standardized, normalised and statistically analysed, without question. This lack of questioning of findings is proposed by me, to be very misleading, to hold back theory development and real understanding of what care is in my critical shift papers. There is originality and contributory value in this work.

4.3 *The role of hermeneutic inquiry*

By Hermeneutic enquiry I mean the role of *interpretation*, underlying our meaning making, and our intention, in differing historical-social-health-care contexts. In particular Heidegger's (1927/1962) Hermeneutic Interpretative Phenomenology (Paper eight 2016:1141), concerned with hidden, less obvious meanings in the 'thing itself' the ontological nature of this, and how only 'interpretation' can make this meaning explicit (Moran, 2000).

Further, the role of preconceptions or 'fore-structures', cultural representations of the disabled and how interpretation in its meaning making *is* in fact 'dasein' that is 'being' 'in itself'. Ontology is then phenomenology, seen by Heidegger (1962) both are inseparable (Heidegger, 1962:59, Guba and Lincoln, 1994, Crotty, 2003:) and how Husserlian Descriptive Phenomenology's use of pure description as method through Bracketing/Epoche, can only ever be partially achieved (paper eight, 2016:1138, Smith, Flowers and Larkin, 2009:25). This applied to psychological research looking at the 'phenomena' itself in its very 'given-ness' with an acknowledged reflexivity toward the research interview, and texts. I look at descriptive and interpretative methods further and in some detail, in research and interviewing in care research in papers five, seven and eight (2010, 2015, 2016). These papers targeted toward 'caring sciences' and social science scholars.

Further questioning over the nature of and determining of what QOL and care are, and explorations into phenomenological methods and conceptualization is attempted by me in the work above. This is needed I believe, to escape the hegemony of quantification in care practices and research. This quantification supports the biomedical model, us/them dualism as a feature of bio-power, and occludes the real lived experiences of participants and their carers. This is seldom voiced, indeed the systems of varying knowledge and power stifles any descent of this kind. I consider drawing attention to this in my work, focussing on measurement to be a contribution in papers five, (2010), seven (2015) and eight (2016), together with informing scholarship in a wider range of practice and social science disciplines, in my publishing strategy.

4.4 Interpretation and Objectivity

In this critical period, a case is made by me for 'hermeneutic phenomenological enquiry and phenomenological psychology' I see this in paper five (2010:3) and state it as a:

> "….re-conceptualization" leading to "accounts of the lived experience and personal interpretations of staff and carers as well as the recipients of care when and if possible".

Even objective indicators of QOL I argue are open to personal nuances, such as taste, the 'eye of the beholder' in paper five (2010:2) making statistical interpretation misleading and problematic in QOL. QOL is a social construct deeply I believe, determined by the personal, the individual, the interpretation.

I am not advocating ignoring the findings of the scientific positivist method but to acknowledge both theory and hypothesis driven 'top down' assessment and data driven 'bottom up' enquiry methods working together giving a fuller picture of this complex world.

For instance a 'triple hermeneutic' issue of interpretation is given in paper five (2010:4) as it applies to staff responding for both Dementia and LD service users in

my work; here I state the "researcher is interpreting the interpretation of the carers interpretation, of the QOL afforded'. I highlight this below in my experience of using the LEC questionnaire as a QOL measure in paper four (2008, Ager, 1998) in my LD private residential care research, with a largely subjective question in Paper five (2010:3)

> "….questions such as 'I feel loved and respected by those that live with me' (relationships subscale of the LEC), one can see that this is far from objective and ultimately a question of hermeneutics that is interpretation per se and inter-subjectivity"

Staff's awareness was noted in that:

> "When this relationship orientated QOL question is asked of staff, the staff themselves knew this was in effect often very hard to ascertain on the behalf of another".

Together with this interpretative issue the general policy environments reliance on numerical quantitative 'data' together with operational policy 'mission' statements which in the field of care, may be an "external relations marketing tool presenting favourable aims and resources to maintain revenue and referral levels" in paper five, (2010:3). This presenting in the 'best light' (Felce and Perry, 1995:60) is a particular risk in the private care sector through misleading operational policy materials interacting with staff fears of accountability/job security, this is also seen in dementia care in terms of institutional maintenance.

A social constructionist perspective is proposed in paper five (2010), where as Gergen (2009:36) puts it, critically assessing "truth, objectivity, reason and knowledge" and manifestations of 'power roles' can explicate caring. Here reality is a co-construction between people instead of an ontological 'out there' to be measured and prescribed. In paper five (2010) social constructionism is set against objective measurement and political pressure to get readily accessible 'results' in care. Later in terms of Foucault's work, people as the 'subjects' of types of knowledge in LD and Dementia care, viewed by a 'clinical gaze' 'objectified'

'medicalised' discourse. 'Personal tragedy' (Oliver and Barnes, 1993) impairment focussed knowledge/s and practices which dis-empower and 'objectify', and dehumanise service users are seen. Yates Dyson and Hiles (2008:250) note "impaired individuals are emergent as objects of thought only within specific systems of knowledge". The deficit model implicit in SRV comes to mind here, with its associated bleak 'othering' terminology. This gap furthered by little knowledge of key principles of caring and QOL within the 'front line' care staff and evidenced practices; particularly in the largely unqualified residential LD care workers I interviewed.

My critical shift is toward a 'bottom up' explorative discovery, not theory driven 'top down' conceptualisation of QOL and care. Glaser and Strauss in their 'discovery of Grounded Theory' (1967) show how theory can evolve from the data itself rather than a priori theory. Charmaz (1983, 2008) using such methodology shows how loss of self can occur through illness (Paper five, (2010:5). I also link interpretative phenomenological analysis (Smith, 1996, 2004) in relation to this first person 'bottom up' hermeneutic and grounded re-conceptualisation, or shift.

Paper seven (2015:427) explores discourse power and phenomenology in deconstructing care towards 'authentic' measurement, in the social construction of care. Care interactions are seen as embodied action and practices and the experience of the carer situated within a 'first person' phenomenological space is given importance here (Paper seven, 2015:427, Woodruff, 2013). The 'authentic' notion of measurement is actualised through the gathering of 'thick data' through Interpretative Phenomenological Analysis (IPA, Smith, Flowers and Osborn 1997). Methods of Discourse Analysis and IPA are proposed as viable ways of seeing caring from the carer's experience, and the cared for, in QOL and care, and importantly the roles care services could play.

4.5 Discourse, Power and Phenomenology

IPA (Smith, 1996, 2004, Smith Flowers and Larkin, 2009:16) informs phenomenological practice by a systematic phenomenological way of 'meaning making'. This achieved through reviewing often semi-structured interview data by a

‘sustained engagement with the text’ (Smith, 1996:9) beginning at the descriptive level describing only the text. Salient features of the text are then subjected to interpretative (hermeneutic) analysis but with traceable links to the text at the descriptive level. Descriptive and interpretative findings link to meaningful overarching themes with theoretical/professional/practice underpinnings. The analyst works then between levels from part (text) to whole (themes) and back again following the ‘Hermeneutic circle’.

From this perspective looking at the social psychology, discourse and practices of care activities, and basic programmes in care, then progress is possible in light of increasing global longevity and technological advancement. Care workers are frequently situated in insecure low paid, poorly trained roles, particularly so in private residential care and negative (sometimes derogatory) conceptions prevail in the wider society of those they care for. The role of discourse in regulating thinking and action is explored in Paper seven (2015:430) particularly in terms of power and its manifestation in care. Gutting (2005:7) notes care is “always also an opportunity for control”. Phelan’s work (2010:893) notes that “taken for granted discourses” of incapacity and decay in old age can ‘implicitly affect’ how nurses *interact* with the elderly. The machinations of power, society, knowledge and discourse are complex but pertinent to deconstructing care.

Phelan’s (2010:898) examination of ‘old age discourse’ shaping nursing practice highlights in bio-medical settings, this “covert production of superior (nurse/doctor) and inferior (client) positions which serve to reinforce an existing status quo devaluing both nursing and the older person”. My experience of Dementia care certainly had instances where prevailing perceptions of the ‘dementing and decaying’ could be seen in senior nursing staff, where social models of care and practices were remarked to be ineffective/not appropriate for this client group. Prevailing fatalistic attitudes toward aging and physical disease could filter down to care provision; such dominant discourses can tacitly influence nursing practice. The opposite positive ‘heterogeneous’ experiences of old age and aging, should be made explicit in nurse training and practice. I note in paper seven (2015:432) that in my QUIS transcripts, often infantalising language was used toward LD and

Dementia participants. Interpersonal (staff-resident) distance and touching operate differently in the care situations I observed, than in the general population.

In paper eight (2016) I examine phenomenological enquiry by types: Descriptive and Interpretative, in their historical development, and confusions between schools. I look closer to phenomenology's applications in terms of caring and QOL, in an attempt to acknowledge what I term the 'invisible' in care. Aspects of intentionality, the phenomenological reduction, and bracketing/epoche, are looked at in terms of Descriptive and Interpretative schools of Phenomenology. Giorgi's (2006, 2008) work on phenomenology's differing methods and their misinterpretations in application to the caring sciences, and care research, is salient here.

I state in paper eight (2016:1136, following from papers five, 2010, and seven, 2015) that phenomenology is a "means of accessing that which escapes traditional empirical measurement in care research". Importantly in this paper a need for a comprehensive model of care is recognised in an increasingly expanding diverse area. The increase in diversity is acknowledged in this work through the recognition of a rapidly growing 'informal' carer population to QOL and care in the UK, a truly comprehensive model of QOL and care should therefore be applicable across an increasingly broad range of scenarios and an increasingly diversity of care providers.

In my early days I note my research was objectivist scientifically framed and organised in papers five (2010), seven (2015), and eight (2016). I note Giorgi's (1995:25) point of the fundamental difference between physical/natural science and psychological research in that the studied focus possesses the "same type of consciousness as the researcher"; in this sense (and others) QOL moves from an objective 'out there' ontology and epistemology to that of the 'lifeworlds' (Dahlberg, Todres and Galvin, 2009) of carers and the cared for.

In paper eight (2016), I acknowledge the differing histories and schools of descriptive and interpretative phenomenology in depth to examine how it could be applied in my early findings. Methodologically, there is little consensus with how to

use the phenomenological method (Giorgi, 2000, Dowling, 2007), the avoidance of what Moran (2000:3) calls 'misconstructions and impositions placed on experience in advance' is key to the process of epoche or bracketing in Husserlian descriptive phenomenology. Giorgi (2008:3) describes bracketing (setting aside) past knowledge "so that full attention can be given to the instance of the phenomenon". If descriptive phenomenology is to be used in QOL and care research it needs noting as Embree (2011:1210) does that there are several 'species of Epoche'. Epoche depending on focus and aims, for example a historical epoche, where "present life is recognised as the effect of earlier times in collective life" so it is suspended (bracketed) in the process, Embree, (2011:124, cited in Paper eight, 2016:1138). Giorgi (2008:2) maintains using 'free imaginative variation' and maintaining a 'disciplinary attitude' later in the process as: "the data will always be richer than the perspective brought to it, but it is the latter that makes the analysis feasible". This provides a method that brings in expertise and knowledge, but after the initial examination by imaginative variation of the subject.

I examine Bevan's (2014:138) proposal of a 'total model' for research using descriptive phenomenology in interviewing, in Paper eight (2016:1139), and important aspects appear pertinent to my past research on QOL. This includes using the natural language of the respondents in interviews Giorgi (2009) also suggests that the final writing of transcript materials prior to analysis should be in the third person to concentrate solely on the focal phenomenon.

My research methods teaching in higher education was in the use of Interpretative phenomenology notably, IPA. Teaching and marking first year to final year dissertations all applying IPA on various interesting projects relevant to my research, increased my critical engagement with this form of phenomenological enquiry. As a method, it appears the most systematic though not overly prescriptive, and as I state in Paper eight (2016:1140) "the crux really is the researcher's interpretation and the bringing in of explanatory concepts and theory in psychology in the final analysis" this intrinsically transcript/data 'bottom up' process could be very useful in analysing QOL, the social construct.

I do point out an area which has always puzzled me in IPA, and that is its reliance on hermeneutics; the interpretation of the interpretations of the respondent by the interviewer and the danger of the loss of the 'essence', of the phenomena. Concepts like QOL and care may be more prone to this distortion in interpretation. This presents a case for user led care research and service user as researcher, minimising levels of misinterpretation.

Applying phenomenological analysis to the 'Lifeworlds' of QOL care research I state in paper eight, (2016:1141):

> '…composing that which is not conventionally recordable, that exists but is made invisible by focussing on pre-ordained measurement, observational categories and functional assessments of service users and providers'

This lifeworld is further obscured by theoretical confusion and conceptions in QOL subjective elements, that are only now given acceptance in QOL research - in LD at least (Brown, Hatton and Emerson, 2013). In my previous research the data could have feasibly been collected as it was, but missing (as it does) essential features of 'atmosphere', such as is the television too loud inhibiting communication? Similar to the recently recommended common sense 'Mum' test (the home good enough for ones mother), and 'smell' test (does the place smell of urine) recommended by the CQC (2017), a rather low QOL bar. There is more to this nuanced 'dark matter', often in care and QOL evaluations, 'dark' in the sense of unseen, unmentioned, not measured, but always there. QOL and care research has been prone to what Van Mannen (2007:19) calls "the dominance of technological and calculative thought" from its social indicators early days to the present day. My work in LD, from SRV research and QOL research to postmodern neoliberal conceptions of care, and QOL together in service developments and growth of qualitative methods carry potential downfalls, noted by Van Mannen (2007:19):

> "…even the increasing popularity of qualitative enquiry has actually resulted in professional practice becoming cemented ever more firmly into

> preoccupations with calculative policies and technological solutions to standards of practice…."

In care and QOL, existential and ontological notions of being and becoming are highlighted in paper eight (2016:1143) within a lifeworld-led model of care such as Dahlberg, Todres and Galvin's (2009), and QOL and importantly Van Mannens' (1999, 2007, 2014) phenomenology of practice. Here social interaction includes 'pathic touch' in caring scenarios. Further I allude to elements of inter-subjectivity of 'being there' for (Fredriksson, 1999, Dewar 2013) the cared for. The highly prescriptive roles of nurse/care worker and patient can limit 'being there for'. Studies of caring conversations like Fredriksson's (1999:1168) find a key role for inter-subjectivity and 'being there' for the patient where a 'transcendence of roles occurs in highly inter-subjective interactions'. This is very different to the neo-behaviourist observation of the QUIS method in my early research. I note that in my observation, lack of interaction, being unresponsive, the many ways of 'not being there' are not recorded and are un-recordable, yet powerful inhibitors of care and well-being in Dementia and LD.

Only through my early path through care research, by publishing and critically looking at the paradigm, could I have reached the 'fork in the road' that this section sets out. This section can be concluded by Guba and Lincolns (2004: 107) and Kuhn's (1962) 'paradigm' including: "a basic belief system based on ontological, epistemological and methodological assumptions. The 'critical shift' to me is a paradigmatic shift on how psychologists and other practitioners could 'measure' community care. From my 'caring, quality of life and service provision: a perspective' Paper five (2010:1) challenging "features of epistemology, methodology and methods" I bring in hermeneutic analysis of the care process, and QOL 'assessment'. Paper seven follows (2015:427) here I propose a 'stripping back', a deconstruction of the paradigm of 'caring' and methodology and measurements. This leads me to paper eight (2016:1134) where I go deeper into phenomenology as it can be applied in caring contexts as a "means of accessing that which escapes traditional empirical measurement" The contribution to knowledge in these papers I believe is how this paradigmatic shift, evidenced by

my three papers singularly and ‘en masse’ can inform how we conceptualize, measure and practice care.

My position framing this research has followed a circular route. Starting with a long-standing personal interest in LD, and community care (see introduction page one). Through empirical dissemination, my original sceptical position returns as to whom care services work for – this to me is not the service user. This disempowerment embodied in a dominant narrative and professional ‘gaze’, with quantification of life’s ‘qualities’. I then reach to discursive analysis and phenomenology, where the service user is the source; voices can be heard, and empowered to be heard. This contrasts with professionals telling service users what they already know, about their challenging lives, my position many years ago.

Section 5: Conclusions and Possibilities

It appears to me, that a focus on ‘measurement’ in evaluating care is missing the essence of care in service systems and human caring interactions; therefore interesting and useful discoveries have yet to be made. Objectivist, inherently therefore ‘objectifying’ epistemological world-views of care, sit within a positivistic atomistic medical model of research and practice. In the contexts of clinical psychology and psychiatry this manifests as quasi-experimental, audit/monitoring methodology and ways of ‘recording’.

From my early position I grew increasingly critically curious as to the nature of care and whether the epistemological position above, theory, and research practice and measurement, can uncover and be fully aware of quality in care; in all its complexities. Though notably in Papers three (2008:40), and six (2014:750) concerning quality of interaction, I do take a symbolic interactionist perspective. My ‘critical shift’ toward a constructionist epistemology, with a hermeneutic and phenomenological view of care, led to ‘acknowledging the invisible’ in Paper eight (2016:1134).

‘Seeing the invisible’ was one theme uncovered in a Scandinavian study using Hermeneutic Phenomenology by Rytterstrom et al (2009), though not in the ‘dark

matter' sense that I have used it in paper eight (2016). Rytterstrom's et al (2009:689) study concerned 'ward caring culture', 'listening and watching' and 'intuitive feelings' in care and listening to how things are done. This concurs with my 'dark matter' analogy, in not being looked for, apprehended or measured in research, but key to inter-subjective responsive care.

It strikes me that this research concerning care staffs 'position' in the care scenario, wards and care systems, (together with quantitative data on job satisfaction, well-being, low pay, high turnover and low morale) could encourage staff empathic understandings of the disempowerment of service users. Notably, UK nursing and care staff are amongst the lowest paid, demoralised workers in the public sector (Jingree, 2015:138, CQC, 2017), disempowered professionally and personally. Relatively speaking, this is a fraction of the disempowerment and lack of voice in service users. My early use of staff stress and wellbeing measures was important in its emphasising stressed demoralised staff will find it harder to deliver good quality compassionate care (Lindesay et al, 1991:730, Dewar, 2013).

A Proposal

The above leads me toward a Quasi-Social Research Model. Here a recognition of the limiting conditions of personal 'differences' and functional issues are acknowledged, with the dis/abling effects of societal perception in post structural discourse, with the political economic conditions and barriers, of Oliver's (2013), realist perspective. With particular emphasis that societal dis/ablement can be further inculcated through practices and staff discourse of dis-care.

Research needs to be trans-disciplinary, in the meeting through more permeable 'fuzzy' disciplinary boundaries, between all care professions. This trans-disciplinary perspective reduces the hegemony of practices, knowledge, and the methodolatory seen in psychological evaluation in community care.

Policy that promotes choice, tolerance, control, social and recreational activities, and that is responsive to emotional and psychological needs is well evidenced

above. Such policy features co-occur with more observed positive and care interaction (paper three, 2007). This policy and observed behaviour interaction more evidenced in smaller (or inter-connected) places encouraging staff to work alone with small groups of service users (paper two 1997, paper three, 2007:38).

Research input to care environments needs to be trans-disciplinary using discursive information and phenomenological accounts, outlined above, over and above 'box ticking'.

Such trans-disciplinary action research could bring in the Hermeneutic meeting of theory and research practice through the creation of a 'Hermeneutic Room' noted by Koskinen and Nystrom (2017:175) where disciplines escape their silos through participatory openness, adopting a dialogue between practice and knowledge, this dialogue being central to understanding in care scenarios, where theory and praxis understandings are focal.

My work above spans a considerable period of my professional life in 'real world' research, evidenced by sole and co-authored outputs and contributions to the field. My early work in LD, in highly under-researched care environments, enhanced knowledge of these contexts, care and QOL. The influence of monitoring per se, changes over time in QOL, together with measurement issues in QOL monitoring add to what is known. My unique observation and differences noted in day-centres, presents a significant contributions to knowledge, of LD day-care services. This followed by my work in Dementia, examining models of care in differing provider groups, and gender differences in interaction advances knowledge in this field significantly. My extensive use of QUIS led me to an attempt to 'make a difference' in my published staff training programme, this took some creative effort and thought, and an original contribution.

My critical shift leading to a re-shaped model of community care could not have happened without my engagement in objectivistic care measurement. Each paper I have produced over time presents my project to continue to push the re-conceptualisation and assessment of care in the community. This positions phenomenological realities of those we care for, and those that care, at the centre

of research, returning to the ‘thing in itself’ toward a post-structural academic force in care research.

My contribution to evidence, and method, and recommendation for policy and practice includes:

My empirical early work shows unstable relationships and opportunities in QOL in residential care in LD, little staff training and qualifications, no operational policies and knowledge of SRV nor QOL. Significant differences in the form and positive nature of interaction by size of day-centre, was observed with a lack of SRV ‘normal role’ provision and basic community contact. My Dementia ‘models of care’ work portrays a ‘social model’ profiling tolerance, choice, control and recreational activity concurring with positive interaction, similar to earlier Domus findings. Importantly my further Dementia work highlights the intersection of gender with Dementia and less communication to, and from female residents.

My contribution to method includes my work on gender adapting the QUIS method to record gender, my original use of QUIS in day-centres in LD, and my proposed training program. My paradigmatic shift toward care research acknowledging data limitations, contributes in proposing phenomenological principles and methods toward a ‘bottom up’ service user led experiential account of care and QOL.

A lack of practice and policy implementation is noted particularly in my empirical QOL research in LD. Policies (see above) in Dementia care which are embedded in a social model are associated with better care outcomes for service users, and staff well-being, and positive social interaction. Importantly my ‘critical shift’ recommends a practice and policy paradigm highlighting service users as central in care assessment with trans-disciplinary dialogue further informing practice and policy, within a re-shaped model of community care.

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Appendix 1: Evidence of Contribution to Publications